

# **Public Health Data Standards Consortium Web-based Resource Center Work Group**

August 22, 2002

11:00 AM to 1:00 PM Eastern Daylight Time.

## **Members**

### **Chair:**

**Tom Doremus**, Information and Communications Specialist  
Public Health Foundation (PHF)

**Suzie Burke-Bebee**, Health Informatics Specialist  
Centers for Disease Control and Prevention (CDC)  
National Center for Health Statistics (NCHS)

**Robert Davis**, Director  
SPARCS, New York Department of Health

**Vicki Hohner**, Confidentiality/Privacy Coordinator  
Washington State Department of Health

**Hetty Khan**, Health Informatics Specialist  
Centers for Disease Control and Prevention (CDC)  
National Center for Health Statistics (NCHS)

**Katherine Kvale, Ph.D.**, Epidemiologist  
Wisconsin Public Health Data Steering Committee

**Anna Orlova, Ph.D.**,  
Associate Professor  
Johns Hopkins School of Public Health

**Tim Stephens**, Director  
Education and Training  
National Association for Public Health Statistics and Information Systems

## **Welcome Johns Hopkins Fellows and brief introductions:**

Anna introduced the Johns Hopkins Fellows who are enrolled in the Health Sciences Informatics program. These students started in July and are doing their orientation in Public Health Informatics, which is part of the Johns Hopkins School of Health and the School of Nursing. This program is one of 15 such programs in health sciences informatics in the country. At the current time it is a post doctoral program, however Johns Hopkins is hoping to establish a similar program at the Masters and PhD level. Their backgrounds are quite diverse:

Karen Assar, MLS - A medical librarian with extensive experience, she is interested in electronic medical records, the UMLS and information retrieval. These are important because of the need for information from the record and the different ways which users search for the information or expect the information to be presented. She hopes to increase the role of librarians in medical informatics,

by demonstrating that the skills and education that librarians receive are a natural fit for the field of medical informatics, and by encouraging more librarians to become involved in medical informatics.

Susan Barned, MLS MS - a medical librarian with a strong background in the basic sciences (including a masters degree in genetics). Her interests are in bioinformatics, consumer health informatics, and immunologic-related diseases.

George Kim, MD - comes to the program after a one-year fellowship in Medical Informatics at the Lister Hill National Center for Biomedical Communications at the National Library of Medicine. Prior to that, he spent over a decade as a general pediatrician and hospitalist at Johns Hopkins Bayview Medical Center. His informatics experience comes from collaborations with the American Academy of Pediatrics (National, District III and Maryland Chapter) and with the group at Johns Hopkins University School of Medicine Department of Pediatrics and Office of Medical Informatics and Education.

Adam Rothschild, MD - received his M.D. from the University of Illinois at Chicago College of Medicine and his B.S. in biology from Tufts University. He recently finished an internship in internal medicine at the University of Pittsburgh. Adam first became interested in medical informatics during his third year of medical school and has been involved in several informatics projects including knowledge-based analysis of LOINC observations, utilization of natural language processing for extraction of therapeutic relationships from MEDLINE abstracts, and assessment and analysis of physician attitudes towards a newly implemented electronic medical record. His interests are primarily in clinical informatics with special interest in electronic medical records and workflow efficiency.

Corey Smith, PhD - recently completed his Ph.D. and an NIMH postdoctoral fellowship in psychiatric epidemiology at the Johns Hopkins Bloomberg School of Public Health. He plans to build upon current research interests in the measurement and classification of psychopathology as a fellow in the training program. Dr. Smith is interested in decision support and other applications of information technology that will lead to improved understanding of mental health problems in clinical and epidemiologic psychiatry.

**Self select as chair (if more than one has an interest a co-lead role or vote will be discussed)**

Tom discussed the opportunity to serve as chair or co-chair of this committee. Tom will be happy to work with the transition to maintain the integrity of the mission. He commented that some of the big projects are out of the way for this WG. The survey has been completed and the initial development of the WRC

site has been accomplished. The WRC is now in the final process of contracting for further development of the site content. Realistically, however, the chair position will take up to 10 hours per week for a twelve-month period. It has been an incredible experience and has been far reaching into the field of health informatics.

No WRC member decided to assume the position, so the WRC recommended that the search be broadened into the entire Consortium. A direct ad on the list serve will be generated to emphasize the critical nature of this position. WRC members suggested that the advertisement emphasize that this workgroup is working to operationalize data standards and make them understandable to individuals. Problems arise when things are not defined well and the web center is critical to create a place where people can get a greater understanding. There are those committee members who work on the technical side and understand platforms, engines, architecture, etc., while there are others who work more on the program side. WRC members would like to see a mechanism in the leadership role to assure that both of these needs are met. A co-chair structure or some other mechanism of support for the leadership position would work to accomplish this. This WG brings a central focus from lots of divergent groups. Tom will put together an explanation and personal insights from this position and will present to the Executive Committee next week. He will put his draft out to the list serve for input from the WRC.

Suzie stated that the contract with Lewin was returned yesterday, but had not been reviewed yet. The bottom line remains the same and she does not expect that there are significant changes. The first of the contracts is funded with internal funding. NCHS is still hoping to obtain outside funding for the second contract. It is possible that the second contract may also be funded from internal funds because the potential funding partner may choose to fund the formation of the 501 (c) 3 corporation rather than the WRC. Further discussion will be held in the Executive Committee call next week.

**Identify tasks with Project Leads and determine interim contact for tasks without identifiable leaders.**

Tom discussed the need for contact persons for the contract with Lewin. The contact person is not assumed to be the acting lead, but would serve as a point person to post questions to the list serve and link the contractor with persons who can answer specific questions. While Tom believed that this work should be spread out, Suzie volunteered to be the contact person for all task groups that do not have designated leadership. It will be necessary to designate content experts from the WRC and from the consortium as a whole to expand the pool of experts. People who would like to assist in any capacity as a resource are necessary, not just task group leads.

## **Revisit need for biographies of Work Group members**

Tom has only received biographies from two WRC members. The bios do not need to be in any specific format, but should be several paragraphs that detail a persons capacities, projects they have worked on in their background, and any expertise they would like to be known by the group. WRC members need to send these bios to Tom along with the number of hours per month they are willing to participate in WRC efforts. These bios will help the leads determine who to call on for a project or issue and how to manage the time requirements of work to be done. Tom will also obtain bios from all members of the Consortium, so that experts are identified in a variety of subjects. Vickie volunteered to review web content for “user friendliness” so that web products are more usable for everyone, not just those with technical or clinical backgrounds. It is also good to get an outside review whenever possible.

Two items from Lewin contract:

1. Kick off conference call with NCHS and others who would like to participate – scheduled for first week in September.
2. First WRC/Lewin joint call would be second week in September. Suzie will list dates available and WRC members should get back to Suzie with availability.

Tom will share bios, as they are received, with other WRC members and with the contractor.

## **Discuss Lewin products on the NCHS and Lewin websites**

When the Consortium was new, Lewin presented materials to help build the Consortium. These materials were also used to help build the WRC. These papers are on the NCHS website and can help WRC members determine the quality and style of Lewin work. Kate commented on other work done by Lewin when they collaborated on a Title 5 project. She felt that Lewin demonstrated a skill of taking complicated work and making it understandable. All WRC members seem to feel that the Lewin work and the contract specifics are good.

## **Discuss/Define roles of Johns Hopkins Fellows**

WRC members feel that it is good for these students to participate with the WRC who are the “movers and shakers” of data standards work. These students have a number of opportunities to work within this process and help with this contract. Students will need to complete a research project over a two-year period and they also need to complete a practicum, which is more limited, but still could involve them in the work of the WRC. Anna lightly indicated she had a Russian way of convincing the students to volunteer to provide free labor to the WRC and hoped she could get them to work with the WRC on this contract. The students were invited to participate on the WRC/Lewin joint call in September in an effort

to shape their role. WRC members are also encouraged to think of opportunities for them to participate. Suzie encouraged them to read the JAMIA article, "User Centered Model for Web Design" to help them determine if this is a project that interests them. Bob suggested that they also consider, in any of their projects, how they would put health informatics into operation. By keeping their thoughts on a higher plane, they can bridge between people who envision health informatics and people who implement. Work on standardizing vocabulary is a good task to help define the work we are doing. Likewise, the vocabulary will be part of the standards that NCVHS is recommending to the Secretary.

One of the students asked about work by Steve Trockman, a fellow at CDC, to create a database of data sets. Suzie will put out his contact information. Suzie also mentioned the e-gov initiative, which created the Consolidated Health Informatics initiative – current focus is vocabulary. Dave Ross, who is putting together a database of software particular to public health, heads another data base effort. This effort has been funded by RWJ so that these databases can eventually be shared. The NCVHS meeting, scheduled for next week, will focus on vocabularies on 8/28 and the Consolidated Health Informatics Initiative on 8/29. WRC members and students are invited to attend the NCVHS meeting or listen on the web site. The NCVHS meeting will also include Colin Price from the National Health Service in the United Kingdom, who has extensive experience and insight into the use of vocabularies. Within 30 days after the meeting, all materials from the meeting are available on the NCVHS web site. Suzie will send out information on these opportunities to the WRC.

#### **Discuss revision of Work Group member listings on NCHS site based on participation status.**

Tom wants to be sure that credit for participation in the WRC will be noted when the NCHS information moves to the PHDS website. Some people named in the workgroup have not participated in the meetings or the minutes. The listing of the members of this workgroup is beneficial to members' professional careers and also helps the WRC or Consortium to obtain funding by demonstrating the type of clout of participating members. WRC understands that some members have had drastic job changes since 9/11 and workloads may have changed, but the credit should be appropriate. If participation in the WRC can be defined in a number of levels, it will help show others that people can participate in many different ways. Any level of participation is important and matters to the total of the work that is done. We need all kinds of volunteer help. Bob and Tom will develop a respectful plan to define these levels, consult members about their participation, and perhaps list any Johns Hopkins Fellows who wish to participate with the WRC.

#### **Other issues from WRC members**

In review of the contract, Kate identifies as many as fourteen tasks, which is more than the membership of the group. While Suzie will serve as the de-facto lead of groups without named leadership, she will need the expertise of the workgroup. The WRC will act as a group consultant. Kate and Suzie will discuss off line.

Tom thanked the group for the opportunity to serve as chair.

### **Action Items:**

- Develop an explanation of the WRC chair position with personal insights into the work for presentation to the Executive committee next week. – Tom
- Comment on the draft put out by Tom - WRC members
- Continue to identify and self identify content experts for the WRC – all WG members
- Send biographies to Tom – All WRC members
- Share bios with WRC members, Consortium and contractor – Tom
- Solicit bios from all Consortium members – Tom
- Consider participation opportunities for JH fellows – All WRC members
- Develop a system to define levels of workgroup participation – Tom and Bob
- E-mail information regarding web sites and contact information for CDC projects and NCVHS – Suzie
- Kick-off meeting with Lewin/NCHS, first week in September – Suzie
- Kick off meeting with Lewin/WRC, second week in September - Suzie

### **Information sent to the list serve by Suzie regarding informatics web sites and contact information:**

1. Dave Ross' group: The Center for Innovation in Health Information Systems (does not yet include the public health software DB project to be done by The Center's new group called the Public Health Informatics Institute). I've found this website to be slow in updating.  
<http://www.centerforinnovation.org/>

2. NCVHS

a. 8/28 and 8/29/02 Subcommittee on Standards and Security agenda (about 30 days after the meeting, the agenda will provide hot links to each speakers presentations/materials):

<http://www.ncvhs.hhs.gov/020828ag.htm>

b. general site for "listening" to NCVHS meetings in the future thru the Internet: <http://www.ncvhs.hhs.gov/> (go to the right "Listen to NCVHS meetings..." following directions for connections)

3. Consolidated Health Informatics (CHI is in the G2B category), one of 24 e-gov initiatives from the White House. (See page 1, last paragraph naming the 24th initiative - "payroll processing"):

a. News Release 10/25/01 <http://www.whitehouse.gov/omb/pubpress/2001-54.html>

b. <<egovstrategy CHI 2001.pdf>>

4. Utah's Data Systems Inventory (Steve Trockman) - just went live 2 days ago: a. <http://health.utah.gov/udohdata> Steve describes this DB as including all of Utah's DOH systems (kind of like states did for Y2K). Interestingly, he is an epidemiologist with the CDC who headed this one-year project (soon to be leaving and going to Maine to do this again in Maine). It was done thru his EPO Fellowship at the CDC thru the Utah DOH (he tells me the inventory was put together essentially in-kind). They've identified 135 systems and 75 stewards of those systems listed (all soon to be added to the Website/DB). Interestingly, the Dept. didn't know exactly how many systems they had until this project. The intent of the system is to be a resource for the Utah's DOH (to prevent duplication of work efforts and to promote standards i.e. uniform data collection). Utah plans to eventually tie into their IBIS (Indicator-Based Information System for Public Health) system, which is a data (not a information system) query DB i.e., querying based on data indicators. Steve will hand over the reins to Barry Nangle (801-538-6907) on 9/6/02. Another intent is for the Utah CIO to promote this model in the other 49 states. This multi-state-wide project is in the visionary stage and the point person for more info will be Barry.

b. IBIS website: <http://health.utah.gov/IBIS-PH>